

May 8, 2015

The Honorable Fred Upton  
Chairman  
Committee on Energy & Commerce  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Frank Pallone  
Ranking Member  
Committee on Energy & Commerce  
2322A Rayburn House Office Building  
Washington, DC 20515

Dear Chairman Upton and Ranking Member Pallone:

On behalf of the Coalition for Pediatric Medical Research, an alliance of our nation's leading children's hospitals and pediatric research institutions; and FightSMA, an organization of families and researchers leading the effort to find a treatment for spinal muscular atrophy, we are writing to thank you for your continued support of pediatric medical research and for including a provision to drive implementation of the National Pediatric Research Network Act (Title II of Public Law 113-55) within the latest 21<sup>st</sup> Century Cures discussion draft. We greatly appreciate your actions to date, and we urge you to retain this provision in subsequent drafts of the legislation as it moves through your committee, and to consider any opportunities to include an explicit authorization of appropriations for the provision.

As you know, the NPRNA enjoyed tremendous bipartisan support as it moved through Congress, and was enacted into law in late 2013. The NPRNA builds upon more than a decade of pediatric research and stakeholder input to develop a meaningful and cost-effective mechanism to strengthen and enhance the National Institutes of Health's commitment to pediatric research. Modeled upon the Comprehensive Cancer Centers and other successful networked research initiatives, the NPRNA at its core seeks to encourage researcher collaboration and coordination by supporting shared core research infrastructure necessary to discharge a robust 21<sup>st</sup> century pediatric research agenda.

Each center or consortia would be comprised of multiple institutions, reflecting the reality that most of pediatric health research involves investigation into rare diseases and disorders, thus necessitating such a collaborative approach to research, particularly clinical studies. In addition to supporting shared core research technologies, NIH funding would also support vital training and development slots for early-career clinician/researchers seeking to focus in pediatrics.

Thanks to your leadership, Congress enacted the NPRNA into law 18 months ago. The time is now to implement this law, and Sec. 1081 of the latest Cures draft will help us achieve this aim.

Thank you, again, for your leadership and support. If you have any questions or would like additional support from the Coalition or FightSMA, please contact Nick Manetto at 202.312.7499 or [nicholas.manetto@faegrebd.com](mailto:nicholas.manetto@faegrebd.com), or Steve Eichenauer at 202-783-2596 or [seichenauer@psw-inc.com](mailto:seichenauer@psw-inc.com).

Sincerely,

Nick Manetto  
For the Coalition for Pediatric Medical Research

Steve Eichenauer  
For FightSMA